

Patients' experiences when accessing their on-line electronic patient records in primary care

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SUMMARY

Background: Patient access to on-line primary care electronic patient records is being developed nationally. Knowledge of what happens when patients access their electronic records is poor.

Aim: To enable 100 patients to access their electronic records for the first time to elicit patients' views and to understand their requirements.

Design of study: In-depth interviews using semi-structured questionnaires as patients accessed their electronic records, plus a series of focus groups.

Setting: Secure facilities for patients to view their primary care records privately.

Method: One hundred patients from a randomised group viewed their on-line electronic records for the first time. The questionnaire and focus groups addressed patients' views on the following topics: ease of use; confidentiality and security; consent to access; accuracy; printing records; expectations regarding content; exploitation of electronic records; receiving new information and bad news.

Results: Most patients found the computer technology used acceptable. The majority found viewing their record useful and understood most of the content, although medical terms and abbreviations required explanation. Patients were concerned about security and confidentiality, including potential exploitation of records. They wanted the facility to give informed consent regarding access and use of data. Many found errors, although most were not medically significant. Many expected more detail and more information. Patients wanted to add personal information.

Conclusion: Patients have strong views on what they find acceptable regarding access to electronic records. Working in partnership with patients to develop systems is essential to their success. Further work is required to address legal and ethical issues of electronic records and to evaluate their impact on patients, health professionals and service provision.

Keywords: primary health care; questionnaire; focus groups; electronic patient records; patient access to records; medical records; electronic records.

Introduction

THE electronic health record is a longitudinal record of a patient's health and health care — 'from cradle to grave'. It combines information about patient contacts with primary health care and subsets of information associated with outcomes of periodic care held in electronic patient records.

Patients have been legally entitled to see their health records since November 1991, and at Bury Knowle Health Centre in Oxford patients have previously held their own paper health records.¹ Access to paper records is now fairly common, but rarely is there access to the full electronic record. Previous studies have included research on: patient access to a short record summary;² access to records on specific or chronic conditions;^{3,4} full access for a limited range of issues;⁵ health professionals' views, without consideration of patient access;⁶⁻⁸ quality of primary care electronic records.⁹ Access to electronic records could: support patients in shared decision making⁴ and in managing their own care;¹⁰ improve communication with health care professionals;¹¹ offer the opportunity to enter information about health, beliefs, values and wishes for care; and allow patients to review their health history and advise clinicians of any changes to health beliefs and wishes or inaccuracies in their health record.¹²

This paper explores the experiences, concerns and wishes of patients given access to their on-line electronic records.

Method

Setting

Bury Knowle Health Centre is an Oxford urban practice covering a varied population, including areas of high and low social deprivation,¹³ with a practice list size of 10 300. The practice has been computerised since 1988 and the full patient records have been stored electronically since 2000. The computer system used at the time of the study was EMIS.

Recruitment

The first 100 available patients attended to view their own electronic records. They were recruited from a postal survey sent to 10% of the adult practice population. These patients were a randomised sample stratified for age and sex. Computer literacy was not a requirement. The survey elicited patients' views about patient access to health records, including electronic records.¹² A postcard was included with the survey, which could be returned separately to indicate whether patients would like to view their own record. Of the first 100 patients who indicated they would like to view their record and were available, 65 of the respondents were

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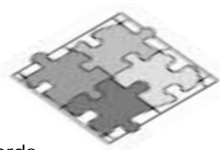
HOW THIS FITS IN

What do we know?

Patients are entitled to see their health records. Record summaries, partial records for certain conditions, and paper records have been used to inform patients and facilitate health care. National Health Service policy is to provide all patients with access to their full primary care health record by 2005.

What does this paper add?

The study focussed on the patients' views when accessing their electronic records for the first time. The in-depth interviews covered a wide range of topics. An example of the type of facilities and security acceptable to most patients is described.



women aged between 18 and 84 years of age (mean = 52 years) and 35 of the respondents were men aged between 19 and 81 (mean = 56 years).

Facilities

Private viewing booths were installed, together with network, computer, biometric (fingerprint scanning) security, and printing facilities. An easy-to-use screen touch light pen was installed with each computer, in addition to a mouse, to give a choice of means to navigate the screens. Security was maintained by a combination of fingerprint biometrics, password, National Health Service (NHS) number and date of birth. Ninety-five patients viewed their records at the practice and five viewed them in their own homes via a secure link to the NHSNet accessed by one of the researchers.

Intervention

The aim was to record patients' experiences when accessing their electronic record for the first time. A semi-structured questionnaire was used to guide a detailed interview with each patient while they viewed their electronic record. The questionnaire was developed to systematically explore views on all sections of the electronic record (registration details, clinical summary, consultations, medication, referrals) as well as to record time taken. Views on access, security, ease of use and whether patients wanted to print their record were also recorded. It was piloted with three patients, reviewed and then re-piloted. Pilot questionnaires were not included in the study. A researcher conducted the interview and offered instructions on how to navigate the record. Where necessary the researcher assisted those few patients who were unable to use the mouse or light pen.

Each patient was instructed on how to access a series of screens and then questioned on their usefulness, ease of understanding, errors and omissions. They were allowed as long as they wished to view each screen, ask questions and make any comments. After viewing their electronic record, patients were encouraged to offer general comments, raise queries and express concerns.

Quantitative data was entered into the SPSS software and simple frequencies derived for the time spent viewing the

records, usefulness of each section, ease of understanding, accuracy, sections printed, and agreement or disagreement with a set of summary statements.

Qualitative data was entered onto a spreadsheet and content analysed to identify key topics and develop a thematic framework. This was agreed by consensus following independent identification of themes by two researchers with all authors agreeing with the final framework.

Seven female patients, who had already viewed their online electronic records aged between 71 and 80 years of age, attended a focus group to further explore key issues surrounding security, confidentiality, consent, control of access and exploitation, receiving bad news, and additional patient requirements. Fourteen patients who initially declined to see their records, consisting of 10 women and four men aged between 50 and 77 years of age, attended separate focus groups. All groups were co-facilitated by a general practitioner (GP) and a researcher. A patient support worker attended to demonstrate the on-line electronic record system. Discussions were recorded and transcribed in full but without patient identifiers. Qualitative data from the focus groups were analysed for themes as described above. Where these overlapped with those explored in the interviews the data was pooled.

The protocol was approved by the Oxfordshire NHS Applied and Qualitative Research Ethics Committee.

Results

Navigation

Most patients found they could navigate around each section of their electronic record and between sections with ease (Table 1). Some patients, especially left-handed people, had problems with using the mouse and opted for the touch screen light pen. Those with little or no computer experience needed a very brief verbal explanation of how and where to 'point and click' or 'point and touch'. Patients spent between 18 and 75 minutes viewing their electronic records while simultaneously being prompted for their opinions. The mean time patients took to view was 33 minutes and the interquartile range was 28 minutes to 40 minutes, with 71% of participants taking 35 minutes or less. The time patients took varied owing to multiple factors, including the quantity of information held within the health record and the patients' level of interest and dexterity. Times were not adjusted to allow for the impact of the interviews, although our observation was that people did not stop and talk, but browsed as they talked:

'I think that the light pen is excellent for older patients.'
(User 31.)

'I don't believe it is user friendly.' (User 28.)

'The layout and design is excellent and it is very user friendly.' (User 47.)

Usefulness

Ninety-nine per cent of patients found at least one section useful, particularly their record summaries and consultation details (Table 1). The main benefits as perceived by the patients are listed in Box 1:

Table 1. Level of patient agreement with questions about accessing their electronic patient record (n = 100).

Question	%
Found it easy to find your way around the record	73
Found registration section useful	85
Found record summary useful	94
Found consultation details useful	90
Found medication details useful	59
Found referrals section useful	42
Found at least one section useful	99
Found registration section easy to understand	94
Found record summary easy to understand	84
Found consultation details easy to understand	80
Found medication details easy to understand	61
Found referrals section easy to understand	41
Found record easy to understand overall	73
Found record difficult to understand overall	5
Worried about security — before seeing record	48
Confident of security in use — after seeing record	61

- Improves doctor–patient relationship by reassuring, improving consultations, and encouraging patients to be better informed about their own health and health care
- Improves accuracy by identifying errors and omissions and improving the completeness of the electronic patient record, and being clear and legible and avoiding the need to read doctors' handwriting. It will also help doctors if records are complete and accurate
- Promotes easier access to information. Patients can review healthcare episodes, dates, and which doctors were seen, including locum doctors. It assists access for emergency services — this is useful when travelling or when moving out of the area
- Improves shared management by facilitating self-monitoring of long-term conditions, by enabling access to vaccination dates, prompting when boosters are needed, clarifying medication details, and clarifying why long-term medication has been prescribed

Box 1. Patient views on advantages of accessing electronic health records.

'Clearer than expected, very easy to understand, very easy to access.' (User 30.)

'On the whole, I think it would prove excellent in building relationships between health professionals and patients.' (Focus group attendee.)

'Great — looks good and I believe it will save time, money, and even lives in the long run.' (User 47.)

'Will people start diagnosing themselves? Will that be detrimental to people's health?' (User 100.)

'I can't believe how many times I have actually been to see my doctor!' (User 47.)

Understanding

Most patients found it easy to understand their records. Where problems arose it was with the record summaries or consultation details (Table 1). Many patients requested explanations of medical terms (42%), abbreviations and acronyms (13%), and information on tests or results (17%)

and metric weight measurements (5%). Clinical questions were referred on to a GP via the routine appointment system. In the early stages the researchers dealt with non-clinical queries. During the course of the study a glossary was developed to explain frequently used terms and tests. In addition, a directory of relevant websites was compiled.¹⁴

'I am sometimes confused and can't remember what doctors said.' (User 71.)

'It is very clear, easy to understand.' (User 87.)

'Medical jargon could lead to misunderstanding and cause worry.' (Focus group attendee.)

Accuracy

Seventy per cent of patients found at least one error or omission. The majority were trivial, especially those in the registration section, such as missing postcodes or outdated telephone codes. Twenty-three per cent of patients found an error or omission that could be described as important (Box 2). Other 'errors' noted by patients were misunderstandings; for example, thinking that 'DNA' referred to genetic tests rather than being an abbreviation for 'did not attend', and differing interpretation of information between patients and health professionals, such as what constitutes 'heavy' smoking:

'You can check up on your details and make sure that they are correct.' (User 8.)

'I broke my collar bone years ago, should that be on "significant past problems?"' (Focus group attendee.)

'I was not born in 1910.' (User 72, aged 42 years.)

'I wish the health visitor had written in my record.' (User 3.)

'I would like to see my record from time to time to check, especially as another person with the same name is registered here.' (User 52.)

Printing

Nearly all were in favour of having print facilities. Thirty-seven per cent used the print facility for printing the following: the entire record (6%); consultation details (21%); summary (15%); medication (4%); and referrals (2%). Two patients considered printing to be a risk to confidentiality. Three said they would take printouts with them when travelling out of the area. One commented that internet access to electronic records would make printing unnecessary:

'I would prefer to have a printout of my records as due to eye problems I would not be able to read them on a computer screen.' (Focus group attendee.)

'Good idea to keep hard copy — easy to read at a later date.' (User 54.)

'I am concerned about the security of printing out a copy, it could fall into wrong hands.' (User 84.)

Security and confidentiality

Prior to viewing their electronic records, 47% had concerns about security. Most were reassured by the use of biomet-

- Significant errors: out-of-date personal data; wrong medication or discontinued medications; consultations listed under the wrong patient; dates and frequencies of recurrences of conditions wrong; referral dates wrong; incorrect site of amputation recorded
- Missing information: medication, vaccinations, allergies, test results, and patient records from before the practice became electronic
- Missing consultations: nurse, health visitor, out-of-hours doctor
- Missing events: adverse reaction to medication, breast screening, operations, tuberculosis, childbirth, premature childbirth, miscarriage, sterilisation, irritable bowel syndrome, severe migraine, glaucoma, fracture, repeated episodes, and minor surgery
- Missing referrals: cardiology, urology, endoscopy, orthopaedic, physiotherapy
- Misunderstanding of terminology: acronyms being misconstrued; medical terms that may have different meanings in common use — for example, one patient understood phlebitis to mean that a flea had bitten her leg!
- Poor patient recall: patients unable to remember what operations were for and their outcomes
- Differences of opinion: about diagnosis, especially for depression; what constitutes heavy smoking; which past events are considered significant and which are listed in the patient summary
- Misunderstanding how information is managed in the NHS: the practice administrative recording system, administrative prompts, transfer of information — for example, from genito-urinary medicine clinics, out-of-hours services and emergency services

Box 2. Significant errors and omissions identified by patients, and causes of misunderstandings.

rics, passwords and NHS numbers, with only 4% being concerned after using the system.

Patients' views were solicited concerning future accessibility of their electronic record via the internet. Fourteen per cent were extremely enthusiastic and had no security concerns, 54% expressed some concerns about security, but felt the concept was acceptable if the security matched that of the NHSNet, and 10% of patients were very unhappy about any use of the internet. Twenty-two per cent did not respond:

'I'm worried about hackers — you hear all sorts of horror stories don't you.' (User 47.)

'Everyone has concerns about computer security. Nothing is really secure whether paper or a computer file.' (User 43.)

'Too much security might make it unnecessarily difficult.' (User 81.)

'What would people want with my health records anyway?' (User 71.)

'I am also concerned about security of paper records in reception and receptionists seeing my records.' (User 49.)

'I would be concerned at the possible lack of security with computer-held records, employers, insurance companies, etc., being able to access supposedly

confidential information.' (Focus group attendee.)

'I don't care who sees them, in fact it would be helpful to me, as a cardiac patient, if they were easily accessible.' (Focus group attendee.)

Consent

Consent was discussed in the focus groups. Patients commonly questioned who could gain access to records. Most patients believe they should have the right to give or withhold consent for professionals to access their electronic record. Views fell within three groups: the majority wish to give access to all health professionals; a few want to give a general consent for doctors but have the option of giving specific consent for other health professionals, such as nurses and physiotherapists; and a very small number want to restrict access to named health professionals only, and although this was a minority view, those who wanted this felt very strongly about it. Almost all patients agreed to emergency services being able to override restrictions on access, but felt that this should be an edited version of the records with restricted access to certain contents; for example, about mental health, sexual health or termination of pregnancy. One patient wished to be 'ex-directory'; i.e., to withhold consent from anyone accessing their record without explicit consent at that time. This patient was prepared to accept the responsibility for the consequences of health professionals not having access to vital information in an emergency.

Although they had not heard of the Caldicott Report, when it was outlined patients supported its principles and recommendations.¹⁵ They welcomed the fact that future NHS user access will be more carefully defined and monitored:

'I nursed my own father for 4 years until he died, he was a diabetic and had major heart surgery in his seventies. It would of made things easier had his medical records been available to me.' (Focus group attendee.)

'There should be a consent form, if possible, within the medical records for who should be able to have access to the record.' (Focus group attendee.)

'It's difficult to find the right time to decide about consent, we change our views throughout our life.' (Focus group attendee.)

Exploitation of the electronic patient record

Patients expressed concerns about the potential commercial use and exploitation of their data. Concern focused predominantly on data being accessed outside primary care by non-medical staff, other patients, employers, insurance companies, pharmaceutical companies, the government, police, social services, and computer hackers. Use for research or epidemiology was acknowledged as legitimate and acceptable, but patients wanted to be informed. They wanted to trust the process of anonymisation and to be assured that if the NHS sold their data the revenue would be used to benefit patients:

'If patients do participate in research for companies then perhaps money should be put into the NHS.' (Focus group attendee.)

'Insurance companies are going to know anyway, they have to tell them about your health now.' (Focus group attendee.)

'What if access was given to their employer and there were things they would rather that their employer didn't know about them?' (Focus group attendee.)

Receiving new information or bad news

Many patients have concerns about receiving new information; for example, test results or correspondence between health professionals. They were especially concerned if the information contained abnormal results or bad news. In the focus groups, patients said they would like to state how new information should be managed. The majority would prefer bad news to be held back until they could be informed by a health professional:

'I believe this is a good idea, and to have access via the internet, however I would prefer getting any bad news from a doctor rather than from a computer.' (Focus group attendee.)

Additional patient electronic patient record requirements

All patients were asked what else they would like to have seen in their electronic records (Box 3). In particular, they wished to write more personal statements about their wishes for care and the level of intervention in the event of serious health conditions, as well as their donor wishes. Patients wished to give a trusted individual access to their electronic patient record and authority to act for them if they were unable to make decisions owing to ill health:

'I would like details on whether test readings are normal.' (User 39.)

'I would like my records to show that in the event of serious loss of quality of life due to old age, injury or disease, I do not wish to be kept alive by medical intervention but would want to let nature take its course.' (Focus group attendee.)

'I have a condition which I self manage with medication from the chemist, I would like to enter that information on the system.' (User 11.)

'I would like links to other useful health websites and more information about symptoms, etc.' (User 34.)

Patients who did not want to see their records

Seventy of the 319 patients who responded within the first month did not want to access their electronic patient record, of whom 55 were happy to discuss their views. The first 14 available volunteers attended one of two focus groups. The groups were different in their overall view. The first group were mostly concerned that wanting to see their records would imply lack of confidence in their GP. The second group included three patients who had had previous contact with health records as health professionals or administrators and were mostly concerned about confidentiality; they were distrustful of computers and computer security. Other rea-

- Additional registration details: next of kin, home circumstances, if widowed, details of children and dependents, cross references to family members' records, workplace details, patient consent, e-mail address
- Improved understanding: explanation of medical terms, use of easy-to-understand language, glossary of acronyms, imperial conversion for weight and height, normal ranges (for example, body mass index) for test results
- On-line services: repeat prescription orders, patient accessed appointment booking, results requests
- Additional health record information: histories going further back in time, blood group, reasons for medications, previous medications
- Options to add information about self-medication, nominated trusted individuals, wishes regarding living wills or wishes in the event of a serious illness regarding care or consent

Box 3. Patient requests.

sons included lack of interest, resistance to change, fear of the content, and visual impairment.

Eleven changed their minds during the course of the discussions when their fears were alleviated or they perceived benefits of seeing their records.

Discussion

Key findings

Almost all patients found their session useful and could navigate around their health record easily. The majority found it easy to understand, although nearly half required clarification via a glossary. Most took about half an hour to view their record for the first time, although this depended on the length of the record and skill using computers. A third of patients used the print facility, but very few printed large amounts.

The advantages perceived by patients include: being better informed about their own health care and medication; being able to identify and correct errors and omissions, thus improving the accuracy and completeness of the electronic patient record (nearly a quarter found significant errors); being reminded of appointments and screening; that life wills, next of kin, and donor wishes could be added; that access to electronic patient records will assist NHS professionals caring for patients outside their own health centre. Before receiving abnormal results or bad news electronically, most patients would prefer to be told by a health professional first.

Patients have concerns about the security and confidentiality of electronic patient records, especially via the internet. However, provided they are confident of the security, two thirds of patients would like to be able to access their record via the internet. Patients wish to be able to give consent as to who can access their electronic patient record.

Limitations and future research

The sample was biased towards older patients and towards women. These were the first patients from a random sample, and may be more curious about their health records than the population as a whole. However, since these are the heavier

users of the service, they are more likely to be representative of the population who wish to access their records, and thus the bias does not decrease the validity of the survey.

More research is required on access to the records of children and dependents, managing the communication of bad news, and patient views on who can access their records and the consent process.

As electronic patient records become accessible it will be important to examine the impact on patients and health professionals and their relationships, together with changes in record keeping, care management, patient involvement, and the impact on consultation time and quality.

Implications for primary care

It had been anticipated that the computer literate would be the group most eager to view their records. However, it was the frequent users of health care who were the first patients, particularly older people, many of whom had no experience of computers.

Many patients are worried by the idea of seeing their own electronic patient record, but their concerns can be alleviated by effective communication of the advantages and by demonstration of the technology involved. This work has also touched on the views of those who did not want to see their records. The participants may be a biased group who, in being willing to discuss their views, may also be more open minded to changing those views than others.

Patient access to electronic records is set to become routine within a few years. Patients needed time and explanations from the non-clinical support workers recruited specifically for this study. Widespread patient access will require the NHS to review its present workforce. Existing non-clinical personnel¹⁶ will require training and reallocation to work with patients if they are to become actively involved in the management of their electronic records and their health care.

Patients' access to their electronic patient records needs to be developed in partnership with patients and health professionals. Our experience is that working with patients keeps us focused on what matters to them. An electronic record based on internet technology that meets the legal, security and Caldicott standards could facilitate the delivery of a more efficient information infrastructure where the electronic record is linked with evidence-based health information sites on the Internet.

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